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ABSTRACT

School personnel who play a significant role in the life of a child face challenges when they encounter the non-medical aspects of coping with a life-threatening illness in a child. Advances in treatment of cancer have resulted in longer survival. When working with students who have cancer, school personnel should stress hope rather than despair. Teachers have had different experiences with death and serious illness and cope differently with grief. Professionals working with children with cancer should recognize their own limitations, acknowledge their fears, and seek help when needed from other professionals. Special attention must be given to the returning adolescent at the secondary school level. Every adolescent with cancer requires a different educational plan. School personnel working with adolescents should strive to: (1) find out the student's specific type of cancer and how it is being treated; (2) designate school personnel who will play a role in dealing with the returning student; (3) establish a plan for communication with the family; (4) meet with the hospital liaison regularly; and (5) plan for the future (college selection, vocational counseling). Many children and adolescents with cancer want desperately to be like their peers. Teachers and school health personnel should provide the child with cancer with as normal an experience as possible. (NB)

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Guest Article

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HELPING CHILDREN DEAL WITH CANCER

by Roger Quinn

Mr. Quinn is a guidance counselor at Sachem High School.

Mr. Roger Quinn, a guidance counselor at Sachem High School.

Teachers, counselors, and other school personnel play a significant role in the life of a child - no less the child with a life-threatening illness. Given adequate preparation, information, and support, educators are an essential and valuable link in the total care of the youngster.

This article considers the challenges that professionals face as we encounter the non-medical aspects of coping with a life-threatening illness in a child.

The incidence of cancer is growing in the United States mainly because of the general aging of the population. Recognizing the current war of statistics over the incidence of cancer, most experts conclude that one in four of us will become a cancer victim. But while more people are dying of the disease - 126,000 deaths in 1985 from lung cancer alone - it is also true that more are living with the disease than ever before (Trafford, p. 26). In addition, researchers also agree that the mortality rate has been reduced among young patients. Only one or two percent of all cancer deaths involve people under thirty (Carey, p. 94). Advances in treatments have generated longer survival and remission periods. Consequently, there is every reason to believe that cancer does not automatically result in the death of an adult or a child. As we come into contact with students who have cancer, and help them to make the transition from high school to college or career, our perspective should be one of hope and not despair. Although a student has a life-threatening illness, he continues to grow and has the same emotional and educational needs as his classmates. How do you feel knowing a child in your classroom has a life-threatening illness?

There comes a time when each of us must personally deal with our feelings about life-threatening illness, death, and dying. The presence in the classroom of a child with cancer stimulates reflection and concern among staff members, not only about the child's future, but also about their own personal feelings and attitudes towards death. A three year study of critically ill children who continued to find satisfaction and fulfillment in school recognized that teachers have had different experiences with death and serious illness and have different means of coping with grief. "It is important to assist teachers to become aware of both their general and specific attitudes and emotional responses toward the concept of death (Spinetta, p. 16)." Such concerns are human reactions and quite normal.

While it is normal to feel overwhelmed at times, it is recommended that the professional recognize his limitations, acknowledge his fears, and turn to colleagues or other helping professionals for assistance. The circumstances lend themselves to collaboration among faculty members in sharing feelings and seeking advice.

At Children's Hospital Medical Center in Cincinatti, health educators have been helping prepare school personnel for the re-entry of students into the classroom. Pam Mattson, a member of the staff, was very willing to discuss the program during a recent telephone interview. It is important that teachers be helped to see the child with cancer as a living, developing child. Such an approach changes personal attitudes. The Medical Center has produced a series of audiovisual materials which explore a variety of issues related to coping

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strategies. For school personnel, two videotapes (one for elementary and one for secondary) are available. The practical issues examined include confronting personal feelings, facilitating communication, designing appropriate academic goals, preparing classmates, and supporting siblings. Mattson also recommends a school inservice program that would promote free discussion and help diffuse difficult situations that might arise in the classroom. Sharing feelings, networking among colleagues, and providing resource materials are valuable pre-planning approaches that serve to support the psychological integrity of school personnel and set the tone for the return of the student.

Sherry Harriton works primarily with adult cancer patients at a hematology-oncology center. Perhaps the only therapist (counselor) working in a private professional setting in Suffolk County, Harriton is available to assist patients with both medical and non-medical needs. A registered nurse with a master's degree in counseling, she finds great personal reward in her work. Harriton offered two equations symbolizing the different views of life-threatening illness. "First, when most people think of cancer, they associate it with pain and equate it to death," she contends (Harriton, personal interview). There is still a taboo in our society that prevents open discussion of cancer, even more so in the case of a child: Cancer = Pain = Death. Although treatment promises prolonged life, there is still the threat of death. During the 1970's, cancer was whispered about in terms of the "Big C"; even the word wasn't mentioned. This concept separates the patient or the person whose illness is in remission from society. It serves to reinforce negative feelings and misconceptions. Fearing that the condition is contagious, even family members may avoid the person with cancer. Harriton offers her own equation, symbolic of a more holistic approach: Cancer = Work = Life. Such an equation conveys the needed sense of hope for both the therapist and the patient. She uses networking, a system of formal and informal relationships with other therapists and a personal supervisor, as a technique for exchanging ideas and experiences. This also helps combat professional isolation.

To this point, we have dealt with the need for a team approach when planning for the return to class of a student with cancer. We must also address specific non-medical concerns at the secondary school level.

Every adolescent with cancer requires a different educational plan just as each requires a different medical treatment. It is important, therefore, to gather as much information about the student as possible. The following action plan may prove helpful:

FIND OUT the specific type of cancer and how it is being treated. The treatment the student is taking, when it is being administered, the potential side effects, and the impact on appearance and behavior. Treatment schedules that may influence attendance. Limitations, if any. What the student knows about the illness. For adolescents, whether the student wishes to talk directly with teachers. The achievement levels of the student's classmates. Size and complexity of the building. Special rules and policies, i.e. rules against wearing a hat, schedule changes. Complexities of the physical plant, i.e. elevator service.

DESIGNATE school personnel who will play a role in dealing with the returning student. Ask the parents to have the caring hospital select a liaison person who will have the responsibility for keeping all of the student's teachers (and teachers of siblings) informed.

ESTABLISH a plan for communication with the family. An attendance policy that encourages school attendance, but is flexible enough to recognize the need for "on demand" home teaching. Realistic academic standards. Acknowledge that beyond the life-threatening illness, the student has special educational needs.

ARRANGE for meetings with the hospital liaison at the beginning and end of each semester. This meeting should include the parents. Consider special needs, including snacks, a place to rest, or just a "time-out" room so that the student does not have to go home unnecessarily.

PLAN for the future. This may involve any or all of the following: college selection

process, vocational counseling and training, and vocational rehabilitation.

Martha Pearse Elliot, in discussing her involvement in the care of her young daughter, raises a number of points that can be applied to the adolescent as well. "If there is one strong emotional need among these stricken children, it is to be like other children." In the case of her daughter, Meredith, school became an obsession, as if she were saying, I can be normal if I can go back to school. "I want to be like everybody else . . . . (Elliot, in Kubler-Ross, p. 144)."

Dr. M. Tameroff at Long Island Jewish Hospital (Schneider Children's Hospital) reminds school personnel that it is hard enough being an adolescent without being a adolescent with cancer. Adolescents are very concerned with their appearance, their performance, and their classmates' opinion of them. Problems often develop when the symptoms become more of a concern than the disease. In the constant battle for normalcy, the student strives to prove that cancer victims are productive and not financial liabilities to society. For just as the adult finds meaning from work, the student finds meaning from attending and achieving at school.

The action plan outlined above depends upon communication. It must be continuous since the school faculty, especially in a larger high school, changes annually and the medical status of the student changes. Spinetta proposes one approach that has been effective with adolescents. Each academic year, a meeting is held with the patient, parents, school counselor, school nurse, and all teachers involved with the student, as well as the hospital liaison. By participating in the conference, the student plays an active role in his educational program. The researcher also found that this approach allows the student and teacher to work together in adopting flexible schedules and class requirements that will allow the student to maintain academic standards and work with the limitations demanded by medical treatments (Spinetta, p. 162). Since graduation from high school and preparation for college or a career are goals of healthy high school students, they should be the goals of adolescents with cancer as well. It is important, therefore, that graduation requirements be fulfilled and college entrance requirements met (Spinetta, p. 164).

Again, throughout this process, everyone benefits from communication and the school takes on increased importance as a normalizing factor in the life of the student.

School activities for the student with cancer are often the most important contact outside of the family. Parents who participate in the care of their child are well informed and usually can be trusted to tell school officials of special needs and concerns. Likewise, teachers and school health personnel should be trusted to provide the child with as normal an experience as possible, without fear of parental retribution (Pearse, p. 178).

Throughout this article, we have discussed a number of misconceptions and common concerns about children and adults with cancer:

- Cancer automatically results in death.
- Cancer is contagious.
- Cancer victims are unproductive.
- Cancer victims are financial liabilities.

Unfortunately, as a recovered cancer patient moves from high school to college or into the work force, he must face discrimination, rooted in erroneous stereotypes about cancer. Examples of this prejudice include:

- Being fired.
- Refusals to hire.
- Demotions and denials of promotion.
- Exclusion from health insurance benefits.
- Undesirable transfers.
- Hostility in the workplace.
- Non job-related medical exams.
- Isolation from fellow workers.

Many people who have cancer, or have fully recovered from it, suffer employment discrimination based solely on their health history. Recently, during a telephone interview, Pam Mattson told me of a college student who was denied entrance into a nursing school because she had a history of cancer. A job, like school, gives people a sense of normalcy, security, and routine. "It enables them to meet other people with whom they might share their joys and sorrows (Norton, p. 4)."

A final comment. This is the last of five articles that I wrote at the encouragement of several friends. They all dealt with the same theme: collaborative efforts in helping, sharing, and growing. The "action plan" discussed above is presented as a suggested model for preplanning. It is a compilation of the research I found rather than a review of an existing program. During my secondary career I have only known three students with cancer. Their teachers, without exception, did everything possible to help those young people. And so this article represents an attempt to draw everything together.

Helping out is not some special skill. It is not difficult to recognize how our mind has been conditioned to deal with unpleasant situations by resisting them. "Our society consumes literally tons of aspirin. It's not just physical pain we try to avoid, but all kinds of unpleasant conditions . . . . (Dass and Gorman, p. 79)." It is difficult facing the suffering of others because we cannot face our own fear and pain. Everyone goes through troubled times. As we help a student or colleague through these difficulties, we are helping ourselves in turn.

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Non-Print

Children's Hospital Medical Center, Elland and Bethesda Avenues, Cincinatti, Ohio 45229.
"Childhood Cancer - Today's Crisis, Tomorrow's Challenge," 30 min.

----- "School: Obstacle or Opportunity?," 30 min.

----- "Coping with Chronic Illness in the Elementary Classroom," 25 min.

----- "Coping with Chronic Illness in the Secondary Classroom," 25 min.

National Cancer Institute. Bethesda, Maryland.
----- "Help Yourself: Tips for Teenagers With Cancer," 15 min.
----- "The Day They Told You," audio play.
----- "Your Family," audio play.
----- "Your Treatment," audio play.
----- "Your Friends," audio play.